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Unique patterns of bereavement in HIV : implications for counselling

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Abstract

***Objective*—The aim of this study was to examine the nature and extent of bereavement problems in HIV+ve clients and the counselling input required.**

***Design*—Ninety individuals referred consecutively for counselling by the medical teams after HIV diagnoses were included in the study. Specific bereavement data was gathered by each counsellor according to schedule and semi-structured interviews for all 90 subjects. These data were analysed in conjunction with medical referral letters.**

***Setting*—HIV positive clients attending for treatment at an inner London Hospital.**

***Subjects*—The subjects were 91% males and 9% females, mean age 33·82 years (SD 7·2, range 15 to 50 years, mode 28). 44·8% were diagnosed as HIV+ve (asymptomatic), 42·5% had an AIDS diagnosis and the remainder were coded as AIDS Related Complex or unclear.**

***Main Outcome Measures*—The subjects were monitored for the presence or absence of bereavement issues, the nature and extent of the reactions and counselling input. The occurrence of single and multiple bereavements was monitored, as were the relationship to the index patient and the health status of the bereaved.**

***Results*—Bereavement was mentioned in 28·2% of referrals from medical practitioners yet 43·1% of the patients had been bereaved and used bereavement counselling. 43% spontaneously commenced the session with bereavement issues. They had lost 348 people (average of 12·9 deaths per person reporting). These were overwhelmingly due to AIDS with only 12 (5·6%) not HIV related. 65% linked the bereavement to their own death. Emotional reaction seemed to be independent of the relationship with the deceased but linked with the diagnosis status of the bereaved.**

***Conclusion*—The emotional consequences of a loss can be severe and long term. The advent of AIDS/HIV has revealed a wave of deaths in a population unused to facing traumatic loss to this extent. There are particular features surrounding AIDS and HIV infection which may differ dramatically from other sorts of loss and challenge previously held notions of bereavement such as the age of the clients, the fact that bereavements are often multiple, the illness state of the bereaved person, the taboo surrounding AIDS which often presents barriers to wider social support and the catalogue of losses which any individual has to face. The frequency and high rate of bereavement, often not noted by referrers, suggests similarity with disaster literature in terms of counselling demand.**

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Introduction

The emotional consequences of a loss can be severe and long term.[1] The fact that they are commonly noted does not detract from their intensity and the severe psychological suffering that individuals report.[2] Workers such as Kubler Ross have set out classic bereavement reactions as they affect an individual. There is much debate surrounding these notions.[3] Although few workers dispute some reaction, the critique is mainly focused on the presence of wide individual variation in reaction rather than any dispute about reaction per se.

The advent of AIDS and HIV infection has revealed a wave of deaths in a population which has not had to face traumatic loss in the past on such an intense scale. For example[4] thoughts of death were found to be age related, with 90% of a student sample rarely thinking about death in a personal way. This is in sharp contrast to the elderly where over 60% had thoughts about death.[5]

There are particular features surrounding AIDS and HIV infection which make the situation dramatically different and challenge previous concepts and notions of bereavement.

Those who die are invariably young. Global statistics show, not surprisingly, that the age range of highest mortality from AIDS is between 20 and 40 years.[6] This closely parallels ages for sexual activity associated with HIV spread. Young children are also dying from AIDS which can be perinatally transmitted.[7] Death from AIDS is the end point of a multitude of losses. HIV infection itself is a diagnosis which heralds losses such as employment, sexuality, relationships, housing and less concrete losses such as hope, a future, control, procreation, social role and health.[8] As HIV is sexually transmitted it is often partners, with sexual relationships, who are now jointly exposed to this disease. Otherwise it is mother/child dyads. This means that bereavement is often multiple. Another unique factor associated with AIDS surrounds the social stigma

and taboo which this disease carries.[9] This not only denies individuals of the needed social support, but renders them vulnerable at the very time that they are most in need. Normile[10] compared parents who had experienced the death of an adult child through cancer with those similarly bereaved by AIDS. Although many aspects of the bereavement and distress were similar for the two groups, they found bereaved AIDS parents reporting scores significantly higher on a series of measures of psychological distress. Grief processes have been described in people with AIDS[11] who were found to show significantly higher levels of depression when compared with a group of diagnosed cancer patients. As the need for social support and dialogue was high, and the presence of social stigmatisation correspondingly high, people with AIDS tended to form close emotional bonding groups. These workers did not explore the impact on such groups of multiple death. Another study[12] examined the grief reaction in 180 gay men whose lovers had died and found that the intensity of grief reaction was related to the caretaking role of the bereaved during terminal illness and the adequacy of support for the practical and emotional burden of caring.

It is not uncommon for individuals to report multiple losses.[13] In a study of emotional adjustment Dean *et al* identified multiple bereavement in a large cohort of New York Gay men.[13] A panel of 624 men had named a mean of 6·2 men dead from AIDS. Of the sample 95% reported losses from AIDS. These workers identified intermittent and chronically bereaved subjects who were highly likely to be involved in caring for other dying friends.

Multiple bereavement from AIDS has no precedent. The only similarities in the literature which can provide any useful insight into such a situation refers to either war time or major disaster situations. Yet even these are limited in their parallel. Disasters are, by their very nature, sudden and unexpected. However traumatic the aftermath, there is no trauma in the preceeding months if the situation was not anticipated. With AIDS, many people know they have an HIV diagnosis and can oscillate through periods of ill-health and sickness during the course of AIDS. Once a disaster has struck, it is usually over, whereas the end of AIDS is simply not in sight. War time carries with it uncertainties but also possible victories. Unlike AIDS, social support during war time is usually high. The passage of time holds out the promise of resolution, yet with AIDS time seems only to alter the situation for the worse. Some studies have started to examine the nature of grief in the presence of AIDS for the longer term survivors,[14] for the lovers of those infected[15–17] and for workers with this population.[18 19] Yet little attention has been focused on the special needs in the face of multiple loss.

This study was set up to examine the extent and nature of bereavement exposure, reactions and adjustments. The extent to which bereavement experiences are monitored by health care professionals and the nature of counselling support will also be examined.

Method

Ninety individuals referred consecutively for counselling after HIV diagnoses were included in the study. Specific bereavement data were gathered by each counsellor according to a schedule and semi-structured interviews for all 90 subjects. These occurred within the normal course of counselling and data were gathered by the individual counsellors. All referrals emanated from the medical clinics or wards. Referrals, as a matter of procedure, are given in writing. After counselling intervention and data gathering a notation was made as to whether bereavement had been mentioned in the referral letter from the medical team. Bereavement counselling for a primary loss was monitored in detail. The extent and nature of other losses were also monitored.

The subjects were 91% males and 9% females. The mean age was 33·82 years (SD 7·2) with a range between 15 and 50 (mode 28). HIV+ve (asymptomatic) was diagnosed in 44·8%, 42·5% had an AIDS diagnosis (the remainder were coded as AIDS Related Complex or unclear).

Results

Extent of bereavement

Of the patients 43·1% had been bereaved and used bereavement counselling within their support sessions. Bereavement was specifically mentioned in 28·2% of referral letters. Thus the medical team saw bereavement as an issue in over a quarter of HIV referrals. In reality it emerged almost twice as frequently. Of counselling sessions 43·1% spontaneously commenced with bereavement issues. Thus bereavement counselling constituted a major component of input with HIV clients.

Table 1 below sets out the relationship between the client and the individual of primary loss.

These figures only represent the first mentioned loss, but are of note. Essentially one is looking at coping strategies and facing a life threatening illness (that is, a time of personal strain and trauma) in the presence of a lost partner (27% of the whole sample) or a lost close friend (a further 11·2% of the entire sample). The majority of the losses (75·6%) were recent (within the first year) and a smaller proportion (12·2%) within 2 years.

Of those who had experienced multiple deaths (n = 27) 348 people had died. This constitutes an average of 12·9 deaths per

Table 1 Relationship of the primary deceased to the HIV + ve client

Relationship	*% of those Bereaved n = 40*	*% of all Referrals n = 90*
Partner	60%	27%
Parent	12·5%	5·6%
Close friend	25%	11·2%
Child	2·5%	1·1

person reporting or a mean of 3·9 deaths for the entire sample. The deaths were overwhelmingly as a result of AIDS (80·8%) with 19·2% reporting non AIDS deaths. Four AIDS related suicides were reported.

Ramifications of bereavement experience

Bereavement counselling is often an opportunity to examine the impact of the death on the future life of the individual. It allows time and space for the patients to review their relationship, their dreams and aspirations, disappointments and guilts. Counselling may facilitate the expression of emotional pain, anguish or anger. Some people experience diverse emotions, either singly, or in sequence, of anger, shock, guilt and depression. Others may experience some of these emotions but may have an individual emotional experience. Of note was the fact that 68·3% of the bereavement sessions incorporated a linkage between the bereavement and the person's own illness. It was also used as an occasion to discuss the individual's own death and mortality in 72·5% of instances.

Table 2 below sets out the extent to which most often recorded emotional reactions were noted. The range of emotions is notable. Counsellors found that 70% of the sample had hardly attained any form of reconstitution. Shock was an overwhelming emotion for 40% of the sample. Denial, although present, was less obvious than other emotions. Depression was noted in the vast majority of cases, with over half the subjects seen as overwhelmingly depressed. Although a quarter of the sample hardly experienced guilt, 44·4% found this an overwhelming emotion. Other emotions were present to an average extent, but no other emotional state was experienced overwhelmingly.

Reactions were similar on all variables when comparing those bereaved with an HIV diagnosis themselves (n = 16), with those who were diagnosed as symptomatic AIDS (n = 16) except for anger. Subjects with AIDS were significantly more likely to show an anger reaction (χ^2 = 6·6 df = 2 p = 0·03). Comparisons were also made between those who were singly bereaved and those who were multiply bereaved. The multiply bereaved were significantly more likely to commence spontaneously the session with bereavement issues (χ^2 = 4·5 p = 0·03). However, the range and intensity of emotional reactions did not differ.

Table 2 Extent of emotional reactions for those using bereavement counselling (n = 41)

Reaction	% Extent of emotion experienced		
	Hardly	*Average*	*Overwhelming*
Shock	37·1%	22·9%	40%
Denial	41·7%	36·1%	22·2%
Anger	27·8%	36·1%	36·1%
Depression	7·3%	34·1%	58·5%
Guilt	25%	30·6%	44·4%
Reconstitution	70%	30%	0
Other emotions	73·7%	26·3%	0

Discussion

These data highlight the widespread nature of bereavement for this sample. Many subjects were multiply bereaved. Efficacy of intervention was not available for the study as it was thought unethical to withhold bereavement counselling. However, the fact that over a fifth of referrals from the medical profession mentioned bereavement and the reality that double this number utilised bereavement counselling tends to suggest a high and growing need for such help with this population.

The range and intensity of emotions may challenge counsellors. They need to be equipped to help clients with overwhelming levels of depression and guilt. Significant variation was found on the anger variable according to diagnosis category. People with AIDS may well feel anger at a medical profession which cannot save their loved ones (and hence themselves). They may feel angry that their partner's death preceded their own. This is often a difficult emotion where the survivor is both saddened by the loss and concerned about his or her future in the absence of a loved one. Having taken care of or nurtured a partner through dying they may feel angry that no-one will be there to do the same for them. It may be very difficult to be the "giving" partner when one is in such need oneself.

Depression may be a culmination of the bereavement and the individuals' personal circumstance. It may well be that the bereavement triggers, perhaps for the first time within a counselling session, an examination of their own illness, mortality and death.

These data suggest that the multiply bereaved do not differ in their reaction from the singly bereaved. It may be that this will change over time. There was no, or little, blunting of emotional reaction. The only difference was that the multiply bereaved were more likely to initiate bereavement counselling. This may signify emotional burden at bursting point or may simply reflect proficiency on the part of clients who have found counselling helpful in the past when faced with losses.

Five of the multiply bereaved individuals were working in AIDS and HIV help organisations. The emotional impact on such individuals may need to be a factor for consideration in the management and support of such organisations. The passage of time may also mark an increased involvement in such organisations and an increased exposure to AIDS related bereavement in HIV+ve clients.

As only three subjects were exposed to suicides, data are unreliable. However, this ought to be monitored in the future as all three subjects had high levels of emotional reactions, especially guilt and depression. All three were multiply bereaved individuals which may have interacted with their ability to accommodate and adjust to the suicide.

Unlike non AIDS bereavement reconstitution was hardly present for 70% of the sample. This, irrespective of relationship with the bereaved and cause of death (AIDS or non AIDS). This would suggest that future theories need to accommodate the health status of the

bereaved as well as variables associated with the person who dies.

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